FILED
DEC 3 1992

3

No. 92-351

IN THE

# Supreme Court of the United States

October Term, 1992

LEONARD E. HELLER, Secretary, KENTUCKY CABINET FOR HUMAN RESOURCES - - - - - - - - Appellant

*versus*

SAMUEL DOE, by His Mother and Next Friend, MARY DOE, Et Al. - - - Appellees

On Writ of Certiorari to the United States Court of Appeals for the Sixth Circuit

## AMICUS CURIAE BRIEF OF THE CONCERNED FAMILIES OF HAZELWOOD CENTER, ICR/MR, INC., (LOUISVILLE, KENTUCKY), THE PARENTS AND RELATIVES OF OAKWOOD FACILITY, ICF/MR, INC. (P.R.O.O.F.), (SOMERSET, KENTUCKY), THE CONCERNED FAMILIES OF OUTWOOD FACILITY, ICF/MR, INC., (DAWSON SPRINGS, KENTUCKY), AND THE CONCERNED FAMILIES OF CENTRAL STATE HOSPITAL, INC., (LOUISVILLE, KENTUCKY) IN SUPPORT OF THE APPELLANT, LEONARD E. HELLER, SECRETARY, CABINET FOR HUMAN RESOURCES

ROBERT L. HELERINGER
Suite 709
310 West Liberty Street
Louisville, Kentucky 40202
(502) 584-3187
*Counsel for Amicus Curiae Parties*

December 3, 1992

WESTERFIELD-BONTE CO., 618 W. KENTUCKY-P.O. BOX 3251, LOUISVILLE, KY.

## QUESTIONS PRESENTED

1. Whether the admissions procedures of state institutional facilities for the severely/profoundly retarded which permit a Court-appointed guardian to voluntarily admit his adult ward for residency and habilitative services violate the Equal Protection Clause of the Fourteenth Amendment to the U.S. Constitution.

2. Does the U.S. Constitution's Equal Protection and Due Process Clauses Prohibit a State's legislative enactment of statutes that confer on parents and legal guardians the status of parties to participate in a retarded family member's judicially-supervised admission proceedings to either obtain or maintain a voluntary placement in a state's institutional facility for severely/profoundly retarded adult individuals in need of habilitative services.

## TABLE OF CONTENTS


| | PAGE |
|---|---|
| **Questions Presented** | i |
| **Table of Contents** | ii |
| **Table of Authorities** | iv |
| **Interest of *Amici Curiae*** | 1 |
| **Summary of Argument** | 3 |
| **Argument** | 5 |
| I. STATE STATUTE THAT DEFINES AS "VOLUNTARY" A PARENT OR GUARDIAN'S APPLICATION FOR PLACEMENT OF A SEVERE/PROFOUNDLY-RETARDED ADULT FAMILY MEMBER IN A STATE INSTITUTIONAL FACILITY FOR SEVERE/PROFOUNDLY-RETARDED INDIVIDUALS DOES NOT VIOLATE THE EQUAL PROTECTION CLAUSE OF THE FOURTEENTH AMENDMENT TO THE U.S. CONSTITUTION | 5 |
| II. PARTICIPATION OF PARENTS/GUARDIANS OF SEVERE/PROFOUNDLY RETARDED FAMILY MEMBERS AS PARTIES IN THE JUDICIAL ADMISSIONS AND/OR REVIEW PROCESS TO OBTAIN OR MAINTAIN PLACEMENT FOR SAID RETARDED FAMILY MEMBER IN A STATE INSTITUTIONAL FACILITY DOES NOT VIOLATE THE U.S. CONSTITUTION | 10 |
| III. THE KENTUCKY GENERAL ASSEMBLY HAS WIDE LATITUDE UNDER THE U.S. CONSTITUTION TO ALLOCATE FISCAL RESOURCES AND ESTABLISH PROGRAMS/HABILITATIVE SERVICES FOR SEVERE/PROFOUNDLY RETARDED CITIZENS RESIDING IN THE COMMONWEALTH OF KENTUCKY | 14 |
| **Conclusion** | 17 |
| **Appendix** | 1a–24a |
| List of Amici | 1a |





| | |
|---|---|
| Kentucky Revised Statute 202B.040(5) | 2a |
| Kentucky Revised Statute 202B.045 | 3a |
| Kentucky Revised Statute 202B.160(3) | 4a |
| Kentucky Revised Statute 202B.230 | 5a |
| Kentucky Revised Statute 210.270 | 6a |
| Kentucky Revised Statute 387.620 | 9a |
| Kentucky Revised Statute 387.660 | 12a |
| Kentucky Revised Statute 387.670 | 14a |
| Testimony of Mrs. Sharon Horton before Kentucky General Assembly, House Judiciary Committee; February 15, 1990 | 15a |
| "Letter to the Editor" of Mr. Thomas Horton, Louisville *Courier-Journal*; June 10, 1989 | 21a |

## TABLE OF AUTHORITIES


| | PAGE |
|---|---|
| **Cases:** | |
| *Addington v. Texas*, 441 U.S. 418, 99 S.Ct. 1804, 60 L.Ed.2d 323 (1979) | 15 |
| *City of Cleburne, v. Cleburne Living Center*, 473 U.S. 432, 105 S.Ct. 3249, 87 L.Ed.2d 313 (1985) | 8, 9, 15 |
| *Cleveland School Board v. LeFleur*, 414 U.S. 632, 94 S.Ct. 791, 39 L.Ed.2d 52 (1974) | 13 |
| *Doe v. Austin*, 663 F.Supp. 597 (W.D.Ky., 1986), 848 F.2d 1386 (6th Cir., 1988) cert.den. 488 U.S. 967, 109 S.Ct. 495, 102 L.Ed.2d 531 (1988) | 6 |
| *Doe v. Cowherd*, 668 F.Supp. 597 (W.D., Ky., 1991), 965 F.2d 109 (6th Cir., 1992) | 10 |
| *Halderman v. Pennhurst*, 707 F.2d 702 (3rd Cir., 1983) | 9, 10 |
| *Harris v. McRae*, 448 U.S. 297, 100 S.Ct. 2671, 65 L.Ed.2d 784 (1980) | 16 |
| *Hodel v. Indiana*, 452 U.S. 314, 101 S.Ct. 2376, 69 L.Ed.2d 40 (1981) | 16 |
| *Holt Civic Club v. Tuscaloosa*, 439 U.S. 60, 99 S.Ct. 383, 58 L.Ed.2d 292 (1978) | 16 |
| *Kadrmas v. Dickinson Public Schools*, 487 U.S. 450, 108 S.Ct. 2481, 101 L.Ed 399, (1988) | 16 |
| *Kremens v. Bartley*, 431 U.S. 119, 97 S.Ct. 1709, 54 L.Ed.2d 184 (1977) | 9 |
| *Lelsz v. Kavanaugh*, 807 F.2d 1243 (5th Cir., 1987) | 17 |
| *Maher v. Roe*, 432 U.S. 464, 97 S.Ct. 2376, 53 L.Ed.2d 484 (1978) | 16 |
| *New State Ice Co. v. Liebman*, 285 U.S. 262, 52 S.Ct. 371, 76 L.Ed 747 (1932) | 15 |
| *Parham v. J.R.*, 442 U.S. 584, 99 S.Ct. 2493, 61 L.Ed2d 101 (1979) | 14, 15 |
| *Philadelphia Police and Fire Assn. for Handicapped Children v. City of Philadelphia*, 874 F.2d 156 (3rd Cir., 1989) | 9 |
| *Schweiker v. Wilson*, 450 U.S. 221, 101 S.Ct. 1074, 67 L.Ed.2d 186 (1981) | 16 |





| | PAGE |
|---|---|
| *Vance v. Bradley*, 440 U.S. 93, 99, S.Ct. 939, 59 L.Ed.2d 171 (1979) | 16 |
| *Wisconsin v. Yoder*, 406 U.S. 205, 92 S.Ct. 1526, 32 L.Ed.2d 15 (1972) | 10 |
| *Youngberg v. Romeo*, 457 U.S. 307, 102 S.Ct. 2452, 73 L.Ed.2d 28 (1982) | 17 |
| **Statutes:** | |
| Kentucky Revised Statutes 202B.040(5) | 5, 6, 7, 8 |
| Kentucky Revised Statutes 202B.045 | 7 |
| Kentucky Revised Statutes 202B.160(3) | 11 |
| Kentucky Revised Statutes 202B.230 | 11 |
| Kentucky Revised Statutes 210.270 | 12 |
| Kentucky Revised Statutes 387.620 | 8 |
| Kentucky Revised Statutes 387.660 | 12 |
| Kentucky Revised Statutes 387.670 | 8 |
| **Other Authorities:** | |
| Supreme Court Rule 37.1 | 3 |

**No. 92-351**

**IN THE**

# SUPREME COURT OF THE UNITED STATES

**October Term, 1992**

---

LEONARD E. HELLER, Secretary, KENTUCKY CABINET FOR HUMAN Resources - - - *Appellant*

*v.*

SAMUEL DOE, by His Mother and Next Friend, MARY DOE, Et Al. - - - - - - - - - *Appellees*

---

## INTEREST OF THE AMICI CURIAE

---

Counsel for both parties to this case have consented in writing to the filing of this brief and true copies of letters indicating said consent are on file in the Clerk's office of this Court.

The *amicus* parties herein, the Concerned Families of Hazelwood Center, ICF/MR, Inc., the Concerned Families of Outwood Facility, ICF/MR, Inc., the Parents and Relatives of Oakwood Facility, ICF/MR, Inc., (P.R.O.O.F.), and the Concerned Families of Central State Hospital, Inc., are all non-profit, incorporated organizations of parents, guardians, relatives, and friends of severe and profoundly-retarded residents of Kentucky's four (4) institutional facilities for severe and profoundly retarded individuals.

There are 220 severely/profoundly retarded residents living at Hazelwood, in Louisville, Kentucky; there are 50 such residents living in a residential unit of Central State

Hospital, also in Louisville; 420 such residents at the Oakwood facility in Somerset, Kentucky, and 80 such residents at Outwood facility in Dawson Springs, Kentucky. All of said state facilities are "Intermediate Care Facilities for the Mentally Retarded." (ICF/MR)

Three individual members (parents) of the *amici* organizations herein were permitted by the District Court below, on November 16, 1983, to intervene in the instant case as *amicus* parties only (R.95: Order) and throughout the 11-year duration of this case have filed, through counsel, briefs, memoranda, and other pleadings at both the trial court and appellate levels all on behalf of the Appellant's position.

The *amicus* parties file this brief to assert the following positions:

(1) Despite the trial court's initial certification of Appellees as a class of *all* retarded residents of the state's institutional facilities, and said court's repeated refusal to allow individual members (parents belonging to the *amici* organizations) to intervene in this case as parties, the *amici* steadfastly believe that the Appellees' actual parents/legal guardians more diligently and faithfully represent the true interests of their severe/profoundly retarded family members than the wholly fictitious "Samuel Doe" and his counsel.

(2) The membership of the *amicus* parties deny that their retarded family members are being "committed," "held," "confined," or otherwise placed *involuntarily* in the state's institutional facilities for the severe/profoundly retarded "against their wills" or are being deprived of their Constitutional rights by any unlawful state action, as alleged by counsel for Appellees. Residents of these facilities are free to come and go fairly at will and parents and family members are allowed entrance to the facilities at any time. More importantly, residents may voluntarily and permanently depart the premises of the facilities at any time with little or no notice to administrators. (R. 98: Appendix to Parents' Dec. 16, 1983 *Amicus* brief in District Court below, at pp. 6-11; Affidavit of Thomas Schmitt)



(3) Parents/Legal Guardians should be allowed to seek the highest quality of care and programs for their severe/profoundly retarded family members in need of such services free of unwarranted and unduly intrusive judicial intervention and scrutiny, whether in an institutional setting or in a "community" placement.

Pursuant to Supreme Court Rule 37(1), the *amicus* parties herein file this brief for the purpose of re-affirming the well-settled Constitutional protection of the family unit. While the *amici* strongly concur with the Appellant's position herein, the Commonwealth's brief may not sufficiently emphasize the role of familial decision-making, *per se*, in the area of maintaining the quality of care and the provision of habilitative services for severe/profoundly retarded, medically-fragile family members. We file this brief to support the sanctity and integrity of the family unit and to deny the unwarranted judicial imposition of an overly-burdensome system that unfairly, unnecessarily, and perniciously divides families and makes Courtroom adversaries of parents and their retarded children.

## SUMMARY OF ARGUMENT

Who decides?

That is the summary of amici's argument herein. Who decides the modality of care for a severely/retarded adult family member? The parents/legal guardians/families of that person or the Federal and State Courts in full-fledged adversary admission and "review" proceedings.

Can the Equal Protection Clause be used to pit family members against one another in these proceedings or does it actually *protect* the decision-making role of a family faced with this most emotional and sensitive crisis?

The *amici* would stress that since their members are the legal guardians for their retarded family members, their role in this process is paramount. The Equal Protection Clause cannot be used to strike down state laws that rea-

sonably, legitimately, and fairly attempt to treat mentally retarded citizens "differently" from mentally-ill individuals. All expert proof establishes that the respective conditions are radically different and *require* different treatments.

It is uncontroverted that when all the reviewing Courts and attorneys have concluded with these proceedings, it is the families that have to deal with the aftermath.

The *amici* hope that this Court keeps these points in mind should other national organizations weigh in with their own *amicus curiae* briefs in opposition to the Appellant's position. These organizations cannot speak for us - only our Kentucky organizations of families of retarded citizens represent our true interests as we seek to obtain the best level of care for our retarded family member. In no other state have families of retarded persons had to cope with the labyrinth of marathon Court proceedings in trying to obtain treatment and habilitative services for their retarded family members. No other state legislature or Federal District Court in the nation has enacted a similar system despite the passage of almost seven years since the first opinion in *Doe*.

The families have endured an 11-year nightmare of Federal Court litigation and the ramifications of six (6) different "memorandum"[1] and appellate decisions that have adversely affected their lives of our retarded family members. (See Horton exhibits, at pp. 15a, 21a of Appendix)

Some of the *amici's* families, through individual parents/legal guardians, attempted to intervene as parties at the outset of this litigation in 1982. Each motion by the parents was denied by the trial court. (R. 91, 92; Memorandum Opinion and Order; R. 95: Order)

---

[1]No trial, in *Doe*, was ever held in the District Court below complete with any "live" testimony. All testimony was by deposition and rulings were issued pursuant to Appellees' numerous motions for summary judgment.



The *amici* have had to endure Appellees' baseless accusations throughout these proceedings that they (the families) are trying to "involuntarily commit" or "confine" their retarded family members in dungeon-like institutions complete with "loss of liberty" and a "curtailment" of their "Constitutional rights." The Hazelwood, Outwood, Oakwood, and Central State facilities are all rated "superior" by State administrative agencies, have innovative and progressive treatment and habilitative programs, and have absolutely no bars on the windows. The "Constitutional rights" of the residents therein are being no more "curtailed" than those of other individuals living in nursing homes, retirement centers, or other examples of congregate living.

The Due Process and Equal Protection Clauses of the U.S. Constitution, far from denying family prerogatives in this area, actually protect family rights to seek appropriate care, services, and programs for their severely/profoundly-retarded family members.

## ARGUMENT

### 1.

### A State Statute That Defines As "Voluntary" a Parent or Legal Guardian's Application for Placement of a Severe/Profoundly Retarded Adult Family Member in a State Institutional Facility For Severely/Profoundly Retarded Individuals Does Not Violate the Equal Protection Clause of the Fourteenth Amendment to the U.S. Constitution

The 1986 Regular Session of the Kentucky General Assembly passed into law House Bill 477 which amended Kentucky Revised Statute 202B.040 (see Appendix, at p. 2a).

The new statute defined the attempted placement of a severe/profoundly retarded individual in a state institutional facility by that individual's family or legal guardian as "voluntary," and thus immune from the normal judicial "commitment" processes statutorily afforded to mentally ill

patients placed, voluntarily or involuntarily, in psychiatric units of mental hospitals.

The District Court below, responding to Appellee's Constitutional challenge of the new act, through the instant case, found the legislation unconstitutional as violative of the retarded individual's due process and equal protection rights under the 14th Amendment. *Doe* v. *Austin*, 663 F.Supp. 597 (W.D., Ky., 1986).

The decision was essentially affirmed by the 6th Circuit Court of Appeals. 848 F.2d 1386 (6th Cir., 1988). This Court declined to grant certiorari. 488 U.S. 967, 109 S.Ct 495, 102 L.Ed.2d 531 (1988).

Certain individual members of the *amici* herein participated in this litigation as *amicus* parties and urged throughout that the law in question passed Constitutional muster.

That this statutory provision ultimately did not survive constitutional scrutiny has led to its logical progeny, the instant appeal before this Court requesting a review of the Kentucky legislature's enactment of statutory amendments to its existing civil commitment laws that attempted (unsuccessfully, so far) to conform said laws to the District Court's original ruling in *Doe*.

The *amici* urge the Court herein to revisit this issue because of its indivisible relation to the issues presented in this appeal. If this Court reverses the lower Courts' rulings and finds that the Kentucky legislature may, constitutionally, confer upon parents/legal guardians the status of parties to fully participate as such in the judicial hearings held to either authorize placement in a state ICF/MR or to review the status of those retarded residents after judicially-approved admission, it should follow that there are no constitutional impediments barring a parent/legal guardian from initially seeking (without prior state court approval) an institutional placement for a severely/profoundly retarded family member in need of such services.



KRS 202B.040(5) stated as follows:

> "The application by parents or guardians for placement for the retarded family member or ward in any mental retardation treatment center shall not be considered an involuntary commitment under this section, provided the retarded family member's application has been evaluated by an interdisciplinary team as defined in KRS 202B.010 and the subsequent admission fully complies with the provisions of KRS Chapter 202B."

House Bill 477 added to this language, the following new text contained in KRS 202B.045:

> (1) Admission:
>
> (a) Patients shall be admitted only upon the approval of a physician. The facility shall admit only persons who have a physical or mental condition which requires developmental nursing services and a planned program of active treatment;
>
> (b) The interdisciplinary team shall:
>
> 1. conduct a comprehensive evalution of the individual, not more than three (3) months before admission, covering physical, emotional, social, and cognitive factor; and
>
> 2. Prior admission define the need for service without regard to availability of those services. The team shall review all available and applicable programs of care, treatment, and training and record its findings;
>
> (c) If admission is not the best plan but the individual must be admitted nevertheless, the facility shall clearly acknowledge that the admission is inappropriate and initiate plans to actively explore alternatives;

These statutory provisions are *prima facie* proof that gaining admission to a state ICF/MR for a severely/profoundly retarded member is not as simple as checking into a hotel. There are numerous codified checks and balances upon a family's desire in seeking an ICF/MR placement.

In addition, as legal guardians, family representatives charged under state law with a fiduciary duty to care for

their retarded family members must comply with a state-court imposed review process of their actions taken on behalf of their ward, primarily through the filing of an Annual Report, which must be completed and then reviewed by a state court ("District") judge for acceptance or rejection. (See KRS 387.670, at Appendix, p. 14a)

Current Kentucky law confers standing on "any interested person" who may compel a state court, after a hearing, to "make any order which the Court deems appropriate and in the best interest of the ward." KRS 387.620(1), (6)(e). (See Appendix, at p. 9a )

With such protective/safeguards already in place, parents/legal guardians should not have to go to trial, with attendant costs, inconvenience, and emotional turmoil, every time they seek to pursue a modality of treatment and care for their severe/profoundly retarded family member. House Bill 477 was merely a legislative attempt to restrict these sensitive family decisions to the venues where they belong: between the families of the retarded individuals and the professionals in the field of treatment of severe/profound mental retardation.

KRS 202B.040(5) and KRS 202B.045 are clearly consistent with the U.S. Constitution's Equal Protection Clause.

> ". . . to withstand equal protection review, legislation that distinguishes between the mentally retarded and others must be rationally related to a legitimate governmental purpose. This standard, we believe, affords government the latitude necessary both to pursue policies designed to assist the retarded in realizing their full potential, and to freely and efficiently engage in activities that burden the retarded in what is essentially an incidental manner."

*City of Cleburne* v. *Cleburne Living Center*, 473 U.S. 432, at 446, 105 S.Ct. 3249, at 3258, 87 L.Ed.2d 313, at 324 (1985) (footnotes omitted).

Kentucky has satisfied the *Cleburne* test in that there are legitimate governmental interests in treating mentally-



retarded and mentally-ill individuals differently as to how members of each group receive treatment.

For the sake of brevity, *amici* will not repeat what the Appellant's brief has stated in detail as far as reciting all the proof that has been adduced at the District Court level as to the undeniable truth that these two maladies are distinctly different, the overriding difference being that mentally-ill individuals, in almost every instance, have the capacity to recover from their illness, while mental retardation is a permanent condition where those afflicted especially at the severe or profound levels often require intensive, permanent treatment and habilitatve services and programs.

The mentally retarded require special and continuing care called "habilitation" to function optimally in society. Habilitation entails "teaching and training the retarded basic life (self-help) and social skills" such as walking, talking, eating, toileting, socializing, using money, traveling and working. Those lessons, however, are not learned permanently - once habilitation ceases, regression occurs. *Philadelphia Police and Fire Assoc. for Handicapped Children, Inc.* v. *City of Philadelphia*, 874 F.2d 156, at 158 (3rd Cir., 1989)

This Court has previously recognized distinctions such as these (retarded versus mentally ill) and approved "different" treatment of these classes of individuals despite Due Process/Equal Protection challenges to said "different" treatment. *Kremens* v. *Bartley*, 431 U.S. 119, 97 S.Ct. 1709, 54 L.Ed.2d 184 (1977); See *Cleburne*, *supra*, 105 S.Ct. at 3258.

Pure Equal Protection considerations aside, for *amici* herein there is a larger, more fundamental issue at stake. *Amici's* fervent plea is that this Court affirm the well-settled "judicial obligation to respect, if not protect, *parental authority* in decisions relating to general family matters because of the importance of the parental role in family

life." *Halderman* v. *Pennhurst*, 707 F.2d 702, at 706 (3rd Cir., 1983) (emphasis added)

In assessing the merits of the challenged sections of the Kentucky legislature's enactment of House Bill 511, in 1990, this Court should also review the prior adverse judicial treatment of that body's 1986 enactment of House Bill 477.

> "Absent a showing of abuse or neglect...the parental right (in chosing treatment plans for retarded family members) remains substantial and may be subject to governmental interference only when such interference is supported by a significant governmental interest." *Halderman, supra*, at p. 709 (3rd Cir., 1983)

**2.**

**Participation of Parents/Legal Guardians of Severely/Profoundly Retarded Family Members, as Parties, in the Judicial Admission/Review Processes to Obtain or Maintain Placement For Said Retarded Family Member In A State Institutional Facility Does Not Violate the Equal Protection Clause of the U.S. Constitution.**

The parental role in family matters is "established beyond debate as an enduring American tradition." *Wisconsin* v. *Yoder*, 406 U.S. 205, at 232, 92 S.Ct. 1526, at 1541, 32 L.Ed.2d 15, at 35 (1972).

Except, perhaps, in Kentucky.

The District Court and the Sixth Circuit Court of Appeals have coldly referred to the parents, relatives, and legal guardians of retarded family members as "third parties" whose "interests may be *adverse* to the person facing *commitment*." *Doe* v. *Cowherd*, 965 F.2d 109, at 113 (6th Cir., 1992) (emphasis added)

These "adverse third parties" are in almost every instance the retarded person's natural parents, most of whom are now aged, and assorted family members who have singularly devoted lifetimes to the constant care of severely/profoundly retarded family members.[2]



*Amici* cannot adequately summarize the dimensions of the devastation visited upon these families in Kentucky by the misguided actions of the Federal Courts below any more succinctly than the testimony of the Horton parents (see Appendix)[3] and the Appellant's accurate assertion that

> "Unlike other States, Kentucky has been forced to stand by as its efforts to provide habilititative services to its needy (retarded) citizens was hamstrung by preliminary injunctions requiring those who would seek such services for the benefit of their mentally retarded sons and daughters march through confusing, complex, unnecessarily expensive and time-consuming procedural obstacles which deter all but the most resolute."

(Appellant's Petition for Writ of Certiorari, at p. 12)

The Kentucky General Assembly's 1990 enactment of amendments to KRS 202B.160(3) and KRS 202B.230 are not violative of the U.S. Constitution.

These legislative enactments provide to parents/legal guardians a "bill of rights" in state judicial admission/review hearings that convene to decide the future (and the location) of a retarded family member's habilitative services.

The challenged provisions permit parents/legal guardians to personally attend these hearings, with legal coun-

---

[2]To see first-hand a glimpse of the effects of the *Doe* decisions, see Appendix herein, specifically the testimony of Mr. & Mrs. Thomas Horton, parents of Tracy, their profoundly-retarded adult daughter.

[3]The Hortons are residents of Louisville and were the first parents/guardians to undergo the endless court proceedings, set up under *Doe*, to have their profoundly retarded daughter, Tracy, admitted to the Hazelwood Center in Louisville.

sel, and to participate in same by calling their own witnesses and appealing any decision they deem adverse to the interests of their retarded son or daughter.

As the Horton case vididly demonstrates, without an express enumeration of these rights, parents and guardians are literally powerless to try to protect, in Court, the *true* interests of their retarded family members during the hearings but are *totally responsible* for carrying out the ultimate mandate of the reviewing state court.

If the rulings of the lower Courts herein are affirmed, *amici* will be effectively stripped of the perogatives vested in them by the state courts as the legal guardians for retarded family members pursuant to KRS 387.660, which sets out in great detail the responsibilities of a guardian including, but not limited to,

> "establishing his place of abode within the state...and to make provision for the ward's care, comfort, and maintenance and arrange for such education, social, vocational, and rehabilitation services as are appropriate and as will assist the ward in the development of maximum self-reliance and independence." KRS 387.660(1), (2) (See Appendix, at p. 12a)

Other key provisions of Kentucky guardianship law recognize the fundamental, vital role of parents/legal guardians in the care of their retarded family members. KRS 210.270 sets out detailed procedures mandating that state officials notify the parents/guardians of retarded family members residing in state ICF/MR facilities if that retarded family member's level of care is to be changed or if that person is being considered for re-classification and movement out of the facility. Significantly, parents/legal guardians are not given a "veto" power over such decisions but are entitled to appeal same through administrative levels and, ultimately, to a state Court.

*Amici* submit that, far from being violative of the U.S. Constitution, this statutory provision (like the challenged legislative acts herein) *enhance* and complement the parents/legal guardian's fiduciary responsibilities and assist them to *comply with the state laws* that *strictly* regulate their conduct as legal guardians.



Again, to reiterate, the state's legislative establishment of two different systems for providing care and treatment of severely/profoundly retarded individuals and for mentally ill people is based on the acknowledged fact that mentally ill individuals may, and in almost every instance do recover from their illness or at least control same with medication. The daunting task before legal guardians of retarded individuals is that their fiduciary duties will *never* end, because retardation afflicting their family member is a *permanent* condition that can, with intensive, unremitting habilitative services, only be abated incrementally, if at all.

That is precisely why the parents/legal guardians need to be involved, as parties if necessary, in any judicial proceeding determining the course and scope of that retarded individual's future care and treatment and in what location or setting.

What the lower Federal Courts have actually done, pursuant to Appellees' meritless challenges, is to violate the due process rights of the parents/legal guardians to make family decisions for their retarded son or daughter. These "family rights of personal choices" are protected by the Due Process Clause of the 14th Amendment. *Cleveland School Board* v. *LeFleur*, 414 U.S. 632, at 639-640, 94 S.Ct. 791, at 796, 39 1..Ed.2d 52, at 57 (1974).

The legislative provisions of House Bill 511, adopted by the 1990 Kentucky General Assembly, only give the parents or legal guardians an opportunity to insure that all of the permissable, relevant, and available evidence is submitted to an *independent* decision-maker and to seek review of any decision which is not consistent with that evidence.[4] Such modest participation of retarded

---

[4]As the Horton case attests, these "rights" are desperately needed by the families undergoing the fairly frequent Federal Court-imposed admission/review proceedings in the state courts.

individual's parents or legal guardians does not impact upon or violate the lower Courts' previous rulings in interpreting the constitutionality of the state's admission procedures to state ICF/MR facilities. The challenged statutes do not provide the parents/legal guardians with a "veto" over any decision affecting their retarded family member, they merely allow the parents/legal guardians to *participate* in the process.

> ". . . our precedents permit the parents to retain a substantial, if not the dominant role in the (voluntary commitment) decision...and that the traditional presumption that the parents act in the best interests of their child should apply." *Parham* v. *J.R.*, 442 U.S. 584, at 604 99 S.Ct. 2493, at 2505, 61 L.Ed.2d 101, at 120 (1979)

**3.**

**The Kentucky General Assembly Has Wide Latitude Under the U.S. Constitution to Allocate Fiscal Resources and Establish Programs/Habilitative Services for Severely/Profoundly Retarded Citizens Residing in the Commonwealth of Kentucky.**

Twice in the last six years, membership of the *amici* have requested that their elected state legislators address the Constitutional "problems" (as defined by the Federal District Court below) attendant to their seeking institutional placements for their medically-fragile, severely/profoundly retarded family members.

On both occasions, the Kentucky General Assembly attempted to address these concerns by enacting legislation - House Bill 477 in 1986 and House Bill 511 in 1990. Each time the legislature acted after holding committee meetings, hearing live testimony, having floor debates and, after considering all the evidence, passed the legislation now challenged herein, by nearly unanimous margins in each House thereof.

It is uncontroverted that this Court has long-recognized, favorably, the prerogatives of the legislative branch of a



state's government to address a wide and limitless range of public interest issues. This tradition dates at least to the time of Justice Brandeis' classic assertion that "It is one of the happy incidents of the federal system that a single courageous state may, if its citizens choose, serve as a laboratory; and try novel social and economic experiments without risk to the rest of the country." *New State Ice Co.* v. *Liebman*, 285 U.S. 262, at 311, 52 S.Ct. 371, at 386-387 76 L.Ed. 747, at 771 (1932) (Brandeis, J., dissenting)

In more recent times, the Court has wisely admonished that

> "How this large and diversified group (of retarded individuals) is to be treated under the law is difficult and often a technical matter, very much a task for legislators guided by qualified professionals and not by perhaps ill-informed opinions of the judiciary..."
>
> ". . . Especially given the wide variation in the abilities and needs of the retarded themselves, governmental bodies must have a certain amount of flexibility and freedom from judicial oversight and limiting of their remedial efforts..." *City of Cleburne* v. *Cleburne Living Center*, 473 U.S. 432, at 442-443, 445, 105 S.Ct. 3249, at 3256-3257, 87 L.Ed.2d 313, at 322-324 (1985)

"Judicial oversight" in this case, for its 11-year duration, has been nothing less than suffocating. Years of work on these sensitive issues by the legislative branch in Kentucky have been unjustly voided upon Appellees' successful Constitutional challenges.

This is precisely the opposite result intended by the aforementioned holdings of this Court, which have decided that states have a legitimate *parens patriae* power in providing care to its citizens who are unable to care for themselves. *Addington* v. *Texas* 441 U.S. 418, 99 S.Ct. 1804, 60 L.Ed.2d 323 (1979)

The *Parham* case termed the state's interest in caring for its retarded citizens as "significant." *Parham* v. *J.R.*, 442 U.S. 584, 99 S.Ct 2493, 61 L.Ed.2d 101 (1979).

The legislative branch is where "the public makes democratic choices among alternative solutions to social and economic problems" over which the Courts exercise "properly" only "a limited review power." *Schweiker* v. *Wilson*, 450 U.S. 221, at 230, 101 S.Ct. 1074, at 1080, 67 L.Ed.2d 186, at 195 (1981).

In a democracy, issues pertaining to sensitive policy choices are to be resolved by the legislature. *Harris* v. *McRae*, 448 U.S. 297, at 325, 100 S.Ct. 2671, at 2698, 75 L.Ed.2d 784, at 811 (1980), quoting *Maher* v. *Roe*, 432 U.S. 464, 97 S.Ct. 2376, 53 L.Ed.2d 484 (1977).

This Court has traditionally respected a presumption in favor of a state's action in cases involving "social or economic legislation." *Kadrmas* v. *Dickinson Public Schools*, 487 U.S. 450, at 462, 108 S.Ct. 2481, at 2490, 101 L.Ed.2d 399, at 412 (1988). The presumption imposes upon challengers the heavy burden of making a "clear showing of arbitrariness and irrationality" in order to overturn the legislation. *Hodel* v. *Indiana*, 452 U.S. 314 at 331-332, 101 S.Ct. 2376, at 2387, 69 L.Ed.2d 40, at 55 (1981). Within this context, a statutory classification violates the equal protection clause "only if the statute's classification rests on grounds wholly irrelevant to the achievement of the State's objective." *Kadrmas*, 108 S.Ct. at 2489 (quoting *Holt Civic Club* v. *Tuscaloosa*, 439 U.S. 60, at 71, 99 S.Ct. 383, at 390, 58 L.Ed.d2d 292, at 302 (1978).

> "We will not overturn such a statute unless the varying treatment of different groups or persons is so unrelated to the achievement of any combination of legitimate purpose that we can only conclude that the legislature's actions were irrational." *Vance* v. *Bradley*, 440 U.S. 93, at 97, 99 S.Ct. 939, at 943, 59 L.Ed.2d 171, at 176 (1979)

The "heavy burden" facing the Appellees in *Doe*, therefore, is to prove that the legislative facts on which the classification is apparently based could not reasonably be conceived to be true by the "governmental decisionmaker." *Ibid*, at 111, 99 S.Ct. at 949, 59 L.Ed.2d, at 184.



Both Sixth Circuit opinions in *Doe* have failed to adhere to this standard of equal proection analysis. In a case similar to *Doe*, the Fifth Circuit Court of Appeals applied the standard correctly in *Lelsz* v. *Kavanaugh* when it held that "in determining whether the state has met its obligations in these respects (programs for the retarded), decisions made by the appropriate professional are entitled to a presumption of correctness." *Lelsz* v. *Kavanaugh*, 807 F.2d 1243 (5th Cir., 1987), citing Youngberg v. Romeo, 457 U.S. 307, 102 S.Ct. 2452, 73 L.Ed.2d 28 (1982)

In its legislative findings, and subsequent enactment of laws related thereto, the Kentucky General Assembly has scrupulously adhered to the *Lelsz* standard and established that sufficient differences do exist between the mentally ill and the mentally retarded that constitutionally permit said legislative body to codify the differing procedures for the admission to state facilities of those two classifications of affected citizens free from unilateral, judicial fiats striking down said classifications as violative of the U.S. Constitution's Equal Protection Clause.

## CONCLUSION

For all the foregoing reasons, the decisions of the Sixth Circuit Court of Appeals and the U.S. District Court below should be reversed insofar as said decisions invalidated the legislature's 1986 amendments to KRS 202B.040(5) and its 1990 enactment of KRS 202B.160(3) and KRS 202B.230.

The *amicus* parties herein would therefore join with the Appellant and ask for the identical relief requested in the Commonwealth's brief.

In sum, the *amici* strenuously deny that any of their retarded family members currently living at one of the state's institutional facilities are being "confined," "held," "committed," or otherwise being deprived of the U.S. Constitution's guarantee of equal protection of the law. The legislative acts challenged herein by counsel for the Appellees *complement* and *strengthen* the role of the fam-

ily vis' a vis' the care and well-being they are morally obligated to provide and maintain for their profoundly-retarded loved ones.

Respectfully submitted,

ROBERT L. HELERINGER
Attorney for *Amicus Curiae* Parties
Suite 709
310 West Liberty Street
Louisville, Kentucky 40202
(502) 584-3187

December 3, 1992

# APPENDIX

## LIST OF AMICI

1. Mrs. Louise Underwood
   President, Concerned Families of Hazelwood Center, ICF/MR, Inc.
   3129 Bank Street
   Louisville, Kentucky 40212

2. Mrs. Virginia Linton
   President, Concerned Families of Outwood Facility, ICF/MR, Inc.
   P.O. Box 144
   Princeton, Kentucky 42445

3. Mrs. Nora Putnam
   President, Parents and Relatives of Oakwood Facility, ICF/MR, Inc.
   683 Elsmere
   Lexington, Kentucky 40503

4. Mrs. Mary Kraeszig
   President, Concerned Families of Central State Hospital, ICF/MR, Inc.
   8812 Tranquil Valley Lane
   Louisville, Kentucky 40299

**KRS 202B.040(5)**

"The application by parents or guardians for placement for the retarded family member or ward in any mental retardation treatment center shall not be considered an involuntary commitment under this section, provided the retarded family member's application has been evaluated by an interdisciplinary team as defined in KRS 202B.010 and the subsequent admission fully complies with the provisions of KRS Chapter 202B."



**KRS 202B.045**

**(1) Admission:**

**(a) Patients shall be admitted only upon the approval of a physician. The facility shall admit only persons who have a physical or mental condition which requires developmental nursing services and a planned program of active treatment;**

**(b) The interdisciplinary team shall:**

**1. conduct a comprehensive evalution of the individual, not more than three (3) months before admission, covering physical, emotional, social, and cognitive factor; and**

**2. Prior admission define the need for service without regard to availability of those services. The team shall review all available and applicable programs of care, treatment, and training and record its findings;**

**(c) If admission is not the best plan but the individual must be admitted nevertheless, the facility shall clearly acknowledge that the admission is inappropriate and initiate plans to actively explore alternatives;**

**202B.160. Hearing procedures. — Rights of guardians and immediate family members.**

• • • • • • • •

(3) Guardians and immediate family members of the respondent shall be allowed to attend all hearings, conferences or similar proceedings; may be represented by private counsel, if desired; may participate in the hearings or conferences as if a party to the proceedings; may cross-examine witnesses if desired; and shall have standing to appeal any adverse decision. (Enact. Acts 1990, ch. 147, § 15, effective July 13, 1990.)

• • • • • • • •



**202B.230 Appeals — Manner — Parties who may appeal. —** Appeals from the final orders or judgments of the District Court made and entered in proceedings under this chapter shall be taken in the manner as other appeals from District Court to Circuit Court. Appeals may be taken by the Commonwealth, the individual who is subject to the proceedings, or the individual's guardian, limited guardian, or other authorized representative. This appeal shall be advanced on the Circuit Court docket without motion or notice.

• • • • • • • •

**210.270. Custodial care of mental patients in private homes, private nursing homes and private institutions — Transfer or reclassification of patient — Procedure.** — (1) The secretary of the cabinet for human resources is authorized to designate such private homes, private nursing homes and private institutions as he shall deem, after a thorough investigation of the personal and financial qualifications of the owners and tenants, the facilities and management, and the desirability of the location of such homes, to be suitable for the placement of patients, including the mentally ill and mentally handicapped and retarded of all ages, outside of the state mental hospitals. The secretary of the cabinet for human resources is authorized to prescribe, from time to time by regulation, standards for the selection and operation of private homes, private nursing homes and private institutions designated for the placement of patients. No home of an officer or employee of the cabinet for human resources or of a member of his immediate family shall be designated for the placement of patients.

(2) Whenever the staff of a state mental hospital has determined that a patient who is not being held on an order arising out of a criminal offense has sufficiently improved and is not dangerous to himself or other persons, and that it would be in the patient's best interest to be placed outside of the hospital in a private home or private nursing home, the hospital shall so certify and authorize the patient to be transferred to a designated private home or private nursing home for care and custody for such length of time as the hospital deems advisable.

(3) No mentally retarded patient lodged in a state institution may have his level of care reclassified nor may he be transferred to a private nursing home or other private institution without first providing ten (10) days' notice by certified mail return receipt requested to the patient's parents or guardian that a reclassification of the patient's level of care or a transfer in the place of residence is being considered.



(4) Any parent of guardian of any mentally retarded patient lodged in a state institution may participate in any evaluation procedure which may result in a reclassification of such patient's level of care or in a transfer in the place of residence of such patient. Such participation may include the submission by the parents or guardian of medical evidence or any other evidence deemed relevant by the parents or guardian to the possible reclassification or transfer of such patient.

(5) If the decision to reclassify or transfer any mentally retarded patient is adverse to the best interests of such patient as expressed by the parents or guardian, they shall be given notice by certified mail return receipt requested that they are entitled to a thirty (30) day period from the receipt of such notice to file with the secretary of the cabinet for human resources a notice of appeal and application for a hearing.

(6) The appeal shall be heard by a three (3) member panel composed of a designated representative of the cabinet for human resources, a designated representative of the state institution where the mentally retarded patient is presently lodged, and a designated neutral representative appointed by the county judge/executive wherein the institution in question is located.

(7) Decisions made by the panel may be appealed, within thirty (30) days from the date of decision, to the circuit court of the county wherein the state institution in question is located, to the circuit court of the county wherein either of the parents of guardians or committee of the patient in question is domiciled at the time of the decision, or to Franklin Circuit Court.

(8) All parents or guardians or committee of a mentally retarded patient lodged in a state institution shall be fully apprised by the cabinet for human resources of their rights and duties under the provisions of subsections. (3), (4), (5), (6), and (7) of this section.

(9) The provisions of KRS 210.700 to 210.760 shall apply to patients transferred to designated private homes and private nursing homes as though such patients were residing in a state mental hospital.

• • • • • • •



**387.620. Petition for relief — Hearing on petition — Judgment or modification.** — (1) A partially disabled or disabled person, his limited guardian, guardian, limited conservator, or conservator, or any other interested person may petition the court for:

(a) Termination or modification of an order of partial disability or disability;

(b) Removal and/or replacement of a limited guardian, guardian, limited conservator, or conservator; or

(c) Renewal of the appointment of the limited guardian, guardian, limited conservator, or conservator.

(2) Petitions pursuant to this section shall set forth:

(a) The name, address of the ward;

(b) The name, address of the limited guardian, guardian, limited conservator, or conservator;

(c) The name, address and interest of the petitioner;

(d) The names and addresses of the ward's next of kin, if known;

(e) The name and address of the individual or facility, if any, having custody of the ward;

(f) The relief requested; and

(g) The facts and reasons supporting the request.

(3) A request under subsection (1) of this section, if made by the ward, may be communicated to the court by any means, including, but not limited to, oral communication or informal letter. If such a request is communicated by means other than a petition, the court shall appoint a suitable person who may, but need not be, an employee of the state, county, or court to prepare a written petition to be filed with the court within seven (7) days following the appointment.

(4) Within thirty (30) days after the filing of a petition, the court shall conduct a hearing at which the ward shall

be entitled to counsel. The time for a hearing may be extended by the court, on motion of either party, for cause. Notice of the time and place of the hearing shall be given by the clerk of the court not less than fourteen (14) days prior to the hearing to both parties and all persons named in the petition. The petitioner shall, upon his motion, be entitled to have the motion for termination or modification determined by a jury.

(5) At the request of any party or on its own initiative, the court may order an interdisciplinary evaluation of the ward. The time period in which the court must review a petition may be extended for an appropriate period of time if an evaluation is ordered by the court. The interdisciplinary evaluation report may be filed as a single or joint report of the interdisciplinary evaluation team, or it may otherwise be constituted by the separate reports filed by each individual of the team. If the court and all parties to the proceeding and their attorneys agree to the admissibility of the report or reports, the report or reports shall be admitted into evidence and shall be considered by the court.

(6) Upon conclusion of a modification hearing without a jury, the court shall enter a written order setting forth the factual basis for its finding and may do any of the following:

(a) Dismiss the petition;

(b) Remove the guardian or conservator and dissolve the guardianship or conservatorship order;

(c) Remove the limited guardian, guardian, limited conservator, or conservator and appoint a successor;

(d) Modify the original guardianship or conservatorship order; or

(e) Make any other order which the court deems appropriate and in the best interest of the ward.

(7) If the original order is dissolved and no further order is issued, the ward shall be relieved of all legal dis-



abilities. The court shall enter an order and judgment restoring to the person all of the rights and privileges of a citizen. The clerk shall note the judgment or modification in the book in which notices of actions and encumbrances are indexed.

(8) The clerk of the court shall transmit a certified copy of the restoration judgment or modification to the originating court, if the judgment or modification is ordered by a court other than the court in which the original judgment was entered.

• • • • • • •

**387.660. Specific powers and duties of guardian.** — A guardian of a disabled person shall have the following powers and duties, except as modified by order of the court:

(1) To take custody of the ward and to establish his place of abode within the state, except that, if at any time a guardian places a ward in a licensed residential facility for developmentally disabled persons, the guardian shall within thirty (30) days of such placement, file with the court notice of the placement, stating with specificity the reasons for such placement, and an interdisciplinary evaluation report detailing the social, psychological, medical or other considerations on which such placement is predicated, a description of the treatment or habilitation programs which will benefit the ward as a result of such placement, and a determination that such placement will provide appropriate treatment in the least restrictive available treatment and residential program. For purposes of this subsection, the interdisciplinary evaluation report may be one performed within two (2) months prior to the placement for purposes of determining whether such placement is necessary and appropriate, or may be an evaluation and assessment provided by the residential facility immediately after placement. Notice to the court shall not be required where the ward is transferred from one licensed residential facility to another.

(2) To make provision for the ward's care, comfort, and maintenance and arrange for such educational, social, vocational, and rehabilitation services as are appropriate and as will assist the ward in the development of maximum self-reliance and independence.

(3) To give any necessary consent or approval to enable the ward to receive medical or other professional care, counsel, treatment or service, except that a guardian may not consent on behalf of a ward to an abortion, sterilization, psychosurgery, removal of a bodily organ, or amputation of a limb unless the procedure is first approved by order of the court or is necessary, in an emergency situation, to preserve the life or prevent serious impairment of the physical health of the ward.



(4) To act with respect to the ward in a manner which limits the deprivation of civil rights and restricts his personal freedom only to the extent necessary to provide needed care and services to him.

(5) To expend sums from the financial resources of the ward reasonable and necessary to carry out the powers and duties assigned to him by the court and, unless a separate conservator has been appointed, to manage the financial resources of this ward.

If a separate limited conservator or conservator has been appointed for the ward, the expenditure of funds by the limited guardian shall be consistent with the duties assigned to and procedures and policies established by such limited conservator or conservator. Conflicts arising between a limited guardian and a limited conservator regarding the expenditure of funds which are unable to be otherwise resolved shall be submitted to the court for resolution. (Enact. Acts 1982, ch. 141, § 17 , effective July 1, 1982.)

**387.670. Annual report of guardian.** — (1) A guardian shall file with the court at least annually a verified report stating:

(a) The ward's current mental, physical, and social condition;

(b) The address of every residence of the ward during the reporting period and length of stay at each residence;

(c) A summary of the medical, social, educational, vocational, and other professional services received by the ward during the reporting period;

(d) An outline of the guardian's visits with and activities on behalf of the ward;

(e) A recommendation as to the need for continued guardianship;

(f) A statement signed by the standby guardian, if one has been appointed, that the standby guardian continues to be willing to serve in the event of the death, resignation, removal, or incapacity of the guardian; and

(g) Other information requested by the court or useful in the opinion of the guardian.

(2) For the purpose of filing the report required by subsection (1) of this section, the guardian shall be given access to records pertaining to the ward held by public or private agencies which contain information necessary for the guardian to perform his duties.

(3) The court shall review the report required in subsection (1) of this section and take whatever action it considers necessary to enhance the well-being of the ward.

(4) In addition to the requirements of this section, a guardian shall comply with the reporting requirements of KRS 387.710 unless a separate conservator has been appointed. (Enact. Acts 1982, ch. 1441, § 18, effective July 1, 1982.)

• • • • • • •



## TESTIMONY OF MRS. SHARON HORTON

Kentucky General Assembly
House Judiciary Committee
February 15, 1990

"Mr. Chairman, Ladies and Gentlemen: I am Sharon Horton from Louisville. I am convinced that the majority of untoward things which happen to us are brought about by benevolent, well-intentioned people.

I hope you will take a few moments to listen to the following story of how my husband and I have been overwhelmed — and we believe abused — by statute 202B.

Our first child, Tracy, was born in 1965 and is now 25 years of age. When she was one year old she was diagnosed as being profoundly mentally retarded and handicapped.

Tracy's health, always very frail, started deteriorating rapidly in 1984 when she was 19 years of age. She suffered frequent pneumonia, chronic bedsores, severe skin allergies, congestive heart failure, swollen limbs and weight loss. To fully understand her health problems you must know that Tracy has a mental age of three months and that she does not walk, talk, toilet, dress, bathe or feed herself. Simply stated, she has needed unremitting 24-hour care for her entire life.

In 1985, frightened and overwhelmed by her health problems, we applied to have her admitted to Hazelwood. A Seven Counties social worker visited our home and started the lengthy admissions process. We were instructed to petition the court to have Tracy declared totally and permanently disabled and have myself named as her legal guardian. The jury trial was held in guardianship court in November, 1985. We were not prepared for what we encountered and were not aware that we would be "prosecut-

ing" our child. It was an extremely painful proceeding which should have been a clue as to what would follow.

The admissions process ground on. Tracy had to be analyzed by a committee here in Frankfort, we had to take her to a social worker, then a psychiatrist, then a physician etc. Finally we were informed in late 1986 that she was approved for admission to Hazelwood and that she was first on the waiting list. After an agonizing delay we were told that due to a "new law" Tracy would have to undergo a series of jury trials prior to her admission, worse, no one was able to answer any of our questions because Tracy was apparently the first to come through the system under this "new law". We were guinea pigs, and we were thrust into the courts unprepared and uninformed. The one thing we did learn was that my status as Tracy's legal guardian counted for nothing, and that the traumatic guardianship trail we had undergone was a totally wasted exercise.

In the summer of 1987, we were dragged through a probable cause hearing, a 60-day commitment trial and a 360-day commitment trial. Finally the process mercifully ended and Tracy was admitted to Hazelwood. The ordeal of being pitted against our own child in an adversary proceeding — in repeated jury trials —— took a heavy toll on us and left us emotionally battered. In the following months, Tracy flourished in Hazelwood's environment. We do not pretend that Hazelwood is right for everybody, but it is right for a select group who need the special services provided there. During the relatively short time Tracy has been there her weight has increased from 69 to 117 pounds, an increase of 70 percent. While her physical condition remains very fragile, we are convinced that Hazelwood saved our daughter's life.

Again in the summer of 1988 we were dragged through the court system again. There was another probable cause



hearing and another 360-day commitment trial. This time, the public defender implored the jury to disregard a mountain of testimony about how much Tracy needed and benefited from Hazelwood's medical services. The jury, with an attorney serving as foreman, ordered her discharged. The verdict defied all the evidence and all logic.

We requested an appeal. Only then did we learn — for the first time — that as parents/guardians we had no standing in these proceedings and were not recognized as legitimate parties. Therefore, we had no "platform" from which to appeal. A verdict had been reached which would have an enormous negative impact on our child for the rest of her life, and we had no legal basis to contest it.

At great personal expense we hired an attorney to represent us. The Hazelwood management, obviously acting on instructions of cabinet attorneys, informed us that if we failed to remove our daughter by the court-ordered date they would initiate "abandonment" proceedings against us. We rhetorically asked them how one could abandon an adult? We further inquired how it came to pass that as Tracy's parents and legal guardians we had no rights and no standing when we sought to place her in Hazelwood, yet we could be prosecuted for failing to remove her?

Our attorney than petitioned the guardianship court to hear our plea; his rationale was that as Tracy's guardians we were bound to comply with the rules handed down by that court regarding strict responsibility for Tracy's care and well-being, and for the submission of annual reports which are reviewed and approved by the court. The judge disallowed our motion, saying he could not overrule another district judge. But before doing so, he made a number of very interesting statements, for example, A) He wondered what is the difference between Tracy and a man with Alzheimer's disease, whose wife can no longer handle him and seeks to place him in a nursing home? Is this not

an involuntary commitment? Should he not have a jury trial before being committed? B) He asked who is to say that Tracy would not oppose being removed from Hazelwood and returned to our home? Who is to say that this is not an involuntary act as far as she is concerned? Who is to say that our home is not more restrictive than Hazelwood? C) He said he agonized over this decision for a week. As legal guardians we had fully complied with his court's orders to take proper care of our daughter and we had in fact subjected her to an annual judicial review by his court. D) He said this law is unworkable and simply must be amended. In dismissing our pleas, he said "For what it's worth, I think my decision stinks." In striving to be brief we have omitted a great deal. Tracy remains in Hazelwood today because we fought the system to a temporary draw. We have withstood 15 trials and/or hearings on Tracy's commitment in the last 19 months. Speaking from personal experience, this entire process is terribly flawed and we submit to you the following observations:

1) The law assumes that parents who seek to commit a child have sinister motives, and that the child must be protected from the parents. This is an outrage, and we believe the law should assume the opposite. With the investigative resources available to the courts, parents could be thoroughly checked out in a few days —schools, neighbors, police, church, social agencies, physicians, employers etc. Past improprieties would quickly surface during a reasonably thorough investigation. In the absence of evidence to the contrary, the parents should be considered to be loving, caring and well-motivated and should not be treated like criminals.

2) The present and future well-being of severely retarded children is much too important to be decided by uninformed lay people, and the juries should be abolished.



The medical testimony is extremely complicated, and this is a matter for only doctors, medical specialists and a judge.

3) We strongly resent and disagree with Tracy's being treated as an adult. She is a three-month old baby in a 25 year old body. Had we admitted her to Hazelwood prior to her 18th birthday we would have been spared much of this grief. By keeping her at home as long as possible, we opened ourselves up to this legal assault.

We do not oppose judicial review of our daughter's stay at Hazelwood: periodic review is a safeguard of Tracy's constitutional rights which will become even more important when her father and I are no longer living. We do, however, oppose annual trials, we oppose jury trials, and we oppose attorneys who use these proceedings as a forum to promote their own social agendas by putting the parents on trial.

A judicial review every three to five years is sufficient for profoundly retarded children, whose progress is measured in millimeters.

5) What these unnecessary trials are costing the commonwealth in time, salaries and judicial resources should be of great concern to you. Tracy's most recent trial lasted two days and tied up a courtroom, a judge, a recorder, bailiffs and several lawyers. In addition, Hazelwood tied up a van, two aides, a social worker, a nurse and a psychologist, all of whom were in court for two days.

Something must be done to correct a system which seems out of control and which is bringing irreparable harm to the very people it is intended to help. There is something terribly wrong with a system which permits a public defender to repeatedly admonish a jury that they absolutely may not and must not permit "what's best for Tracy" to enter into their deliberations. We beg you, our lawmakers, to take up this challenge and do "what is best" for the Tracy Hortons of the Commonwealth.

We thank you for permitting us to state our case and ventilate our anger and frustration.

Thank you very much, Mr. Chairman."

(R. 202: Appendix to Parents' June 14, 1990 *Amicus* Brief in District Court below, at pp. 9a-17a).



**LETTER TO THE EDITOR OF MR. THOMAS HORTON, LOUISVILLE *COURIER-JOURNAL* JUNE 10, 1989**

**". . . Parents' 'ordeal'**

Your May 22 story and follow-up editorial about our daughter Tracy shed light on the continuing controversy over the care of the retarded. However, we feel they did not sufficiently illuminate the cruel hoax currently being played upon the parents of those children.

The final chapter of the Tracy Horton tragedy is yet to be written. Sometime soon, various and sundry judges and lawyers will decide her fate. The opinions of her parents, doctors and nurses, i.e., her care-givers, will neither be solicited nor considered.

Tracy's is not only the story of the failure of our judiciary and government to meet the critical needs of our retarded children; it is the story of the abrogation of our long-standing commitments to them. It is the story of our unfortunate capacity to inflict harm upon those in need, all in the name of helping them.

Tracy was profoundly retarded at birth. Not unlike modern parents, we would have preferred a perfect baby; however, we accepted her as a gift to us and set about to rear her as we were given the right to do so. All of the doctors who examined her urged us to institutionalize her right away in order to spare us heartache later on. We would not consider it. Tracy was part of our family, and we vowed to care for her for as long as possible, a promise we were able to keep for 22 years. In contemplating our recent devastation at the hands of the court system, we would not counsel other parents to follow our example.

Rearing Tracy was extremely difficult, but no one promised us it would be easy. Community resources were practically nonexistent, and sources of respite workers al-

ways dried up by the time we learned of them. Parents of retarded children quickly learn that it is easier to stay home than to suffer the frustration of finding sitters, who tend to back out when they learn the child is retarded. Parenting such a child requires enormous sacrifice, but the reward comes with the special bonding that occurs between parents and child — a bonding that the courts apparently do not value.

As your article noted, Tracy has no selfhelp skills whatever and has required unremitting care during her entire life. Compounding those problems in recent years, her always-frail health deteriorated dramatically. She was in a downward spiral, which we could not reverse. A range of medical problems such as hers requires ongoing professional care, which distraught parents are ill-equipped to administer. Over time, and after more than one death watch, we reluctantly concluded that she would not survive if she remained at home.

Fortunately, the people of Kentucky — in their goodness — have put programs and facilities like Hazelwood in place to care for our retarded children. These facilities could be much better, but they exist and they do a creditable job with the meager resources available to them. We began the agonizing process to have Tracy admitted. The procedure for evaluating her need for Hazelwood's services, and her qualifications for admission, were extensive and thorough. But as tedious as the process seemed, it was carried out with a high degree of compassion and sensitivity. This sympathetic treatment 'validated' our long-held belief that if we did the best we could for our child for as long as possible, the system would reach out to us in out time of need. Our naive faith in the system would soon be shattered.

The experts determined that Tracy met every requirement for admission, and after several months she was first



on the waiting list. Up to this point the system had worked splendidly. Careful evaluation had ensured that she truly needed Hazelwood's special services, an assurance that the taxpayers are entitled to.

Suddenly, the court changed the rules. We learned that parents who seek to admit their child to an institution would now be assumed to have alterior motives. The court would appoint a lawyer to "protect" the child from the parents. Two jury trials would be required annually thereafter. The parents would be given no standing in the proceedings other than as spectators, and their rights as legal guardians would be discarded. If the parents believed that the jury verdict was harmful to the child's health and well-being, they would have no right of appeal. If the parents had questions, there would be no answers. If the parents needed legal assistance, none would be available.

The spirit of compassion that we had experienced previously now evaporated with the new legal requirements, and we were greeted in court with hostility and scorn that shocked our sensibilities. The jurors were warned that they would be derelict in their duty if they arrived at their decision by considering "what is best for Tracy." Referring to the mother who has fed Tracy more than 25,000 meals — one spoonful at a time — the public defender repeatedly portrayed her to the jury as an uncaring parent who was seeking to lock her child away in a dreary institution and forget about her.

The ordeal of being pitted against our own daughter in an adversary proceeding — in endless jury trials — left us emotionally devastated. We would not comprehend how a legal system could inflict this kind of pain on the parents of retarded children. We commenced our journey through the courts racked with guilt and brokenhearted about "giving up" our daughter, and frightened for her future safety, and then found ourselves battered in trial after trial by a

system that we had turned to for help. Is it no wonder that parents of retarded children feel so helpless and isolated?

Profoundly retarded children are the single most disfranchised group in our society, and as such they deserve every consideration we give them. Those who can function in the community should be given the opportunity to do so. Those, like Tracy, with ongoing medical problems and those who need the protection of a sheltered environment should have appropriate facilities made available to them. We parents of these children have a genuine need to rear them ourselves if we are capable, and after doing so we do not expect you to summon us to the courthouse and pin medals on us; however, neither do we expect you to haul us into the courthouse and bludgeon us.

Those who act as if winning a case were more important than allowing a sick child to receive medical care, those who oppose our will regarding our retarded child's health and safety, those who implore juries to disregard all medical testimony, and those who contend that they — and not the parents — know what's best for her, say that they are doing so to protect her civil rights. We parents, on the other hand, want desperately to protect her life. Tracy seemingly cannot be permitted to have both.

/s/ Tom Horton
Louisville, Kentucky 40223"

(R. 202: Appendix to Parents' June 14, 1990 *Amicus* brief in District Court below, pp. 18a-21a)